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ABSTRACT

This is a report submitted by Representative Dingell of the Committee on Energy and Commerce concerning the Protection and Advocacy for Mentally Ill Act of 1985. The purpose of this bill is to assist the states to establish advocacy systems on behalf of mentally ill persons who are or have been institutionalized and to provide emotional, educational, and practical support for mentally ill persons exhibiting memory disorders such as Alzheimer's Disease. Amendments in the form of specific wording changes are presented. The report summarizes the background of the legislation, previous hearings, committee findings, and cost estimates from the House committee and Congressional Budget Office. An analysis of the bill is included which defines many of the bill's terms. Views dissenting with parts of the bill are presented by Representatives Bilirakis and Waxman. A brief statement of opposition to the entire bill signed by 11 Congressmen concludes the document. (ABL)

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PROTECTION AND ADVOCACY FOR MENTALLY ILL
INDIVIDUALS ACT OF 1985

NOVEMBER 21, 1985.—Committed to the Committee of the Whole House on the State
of the Union and ordered to be printed

Mr. DINGELL, from the Committee on Energy and Commerce,
submitted the following

REPORT

together with

ADDITIONAL AND DISSENTING VIEWS

[To accompany H.R. 3492]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 3492) to assist the States to establish and operate protection and advocacy systems for mentally ill individuals and to promote family support groups for Alzheimer's disease patients and their families, having considered the same, report favorably thereon with amendments and recommend that the bill as amended do pass.

The amendments (stated terms of the page and line numbers of the introduced bill) are as follows:

Page 2, line 2, page 3, line 6, and page 8, line 1, insert "board and care home," after "nursing home,".

Page 2, line 20, strike out the period and insert in lieu thereof the following:

or, if the Governor of the State designates a State mental health protection and advocacy system as the eligible system for the State, such designated State system. The Governor of a State may designate a State mental health protection and advocacy system as an eligible system under this Act if the State system is in effect within 90 days of the date of the enactment of this Act, provides

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services throughout the State, meets the requirements of section 103(b), and is principally supported by State funds which have been appropriated by October 1, 1985, for the provision of mental health protection and advocacy services by such system.

Page 2, line 25, strike out "and", in line 3 on page 3 strike out the period and insert in lieu thereof "; and", and add after line 3 the following:

(C) for whom a legal guardian, conservator, or other legal representative has not been appointed or who is not an inpatient in a State which has in effect a protection and advocacy system similar to the system for which assistance is provided by section 3.

Page 3, line 2, insert "board and care home or a" before "community".

Page 3, insert before line 4 the following:

In the case of individuals in a State in which the Governor had made a designation described in paragraph (2), such term means an individual described in only subparagraphs (A) and (B).

Page 3, insert after line 24 the following:

(7) The term "board and care home" means a facility licensed or regulated by a State under section 1616(e) of the Social Security Act.

Page 5, line 11, insert "board and care homes or" before "community".

Page 5, line 20, strike out "residential" and insert in lieu thereof "hospitals, nursing homes, or board and care homes or community".

Page 9, line 13, insert "board and care home," after "nursing home,".

PURPOSE AND SUMMARY

The legislation creates two authorities for mentally ill persons and their families: One provides for the protection of and advocacy on behalf of mentally ill persons who are or have been institutionalized and provides for advisory councils made up of such persons and their families. The other provides for the educational, emotional, and the practical support of those persons who have particular mental illnesses that result in memory disorders, including the disease known as Alzheimer's Disease, whether or not those persons have been institutionalized; such support is also to be extended to family members of such persons.

BACKGROUND AND NEED FOR THE LEGISLATION

In late 1984 and early 1985, the Subcommittee on the Handicapped of the Senate Labor and Human Resources Committee undertook an intensive investigation of the care and treatment of mentally ill persons in institutions. That Subcommittee's report (S. Hearing 99-50) reported serious instances of abuse and neglect of

such institutionalized persons. The report also concluded that protection and advocacy services were needed to investigate and prevent further instances of abuse and neglect.

On August 2, 1985, the Subcommittee on Health and the Environment of the House Energy and Commerce Committee held hearings on H.R. 3148, a proposal to create a program of protection and advocacy services for mentally ill persons analogous to the services currently available for persons with developmental disabilities. At that hearing, the Subcommittee received testimony from persons who were themselves once institutionalized for mental illness, from family members of such persons, from the National Association of State Mental Health Program Directors, from public advocates for mentally ill and/or developmentally disabled persons, and from the psychiatric profession.

All witnesses attested to their experience with or familiarity with the abuse—physical, emotional, and sexual—and neglect of mentally ill persons in institutions and recently discharged from institutions. The inadequacy of existing internal and volunteer patient representative programs was discussed. All witnesses supported the creation of protection and advocacy services for mentally ill persons.

Protection and advocacy services for the developmentally disabled have been a condition of a State's receipt of funds under the Developmental Disabilities Assistance and Bill of Rights Act ("the D.D. Act") since 1975. The D.D. Act and its State Protection and Advocacy agencies (P&A's) were last reauthorized in 1984 (P.L. 98-527). The D.D. P&A's have been a successful and well-received program, widely accepted by disabled persons and their families and by providers of services, as well as by State and Federal authorities.

Alzheimer's Disease is a mental condition or disorder that now affects some 2.5 million middle-aged and elderly Americans and their families. It is characterized by a deterioration of cognitive functions such as memory, attention, and judgment. The cause of this mental disease is unknown; its course is progressive and irreversible. Eventually Alzheimer's victims cannot care for themselves and are forced to rely on their families and others for assistance in maintaining virtually all activities of daily living.

Private health insurance and the Medicare and Medicaid public health financing programs provide little or no coverage for Alzheimer's-related services. Consequently, the families of these patients are often left to fend for themselves in obtaining information about the disease and in providing care to their loved ones. Support groups organized in an appropriate setting can provide access to needed information as well as to individuals and their families who are undergoing the difficulties of confronting this debilitating disease.

HEARINGS

On August 3, 1983, the Subcommittee held joint hearings on Alzheimer's Disease with the Subcommittee on Health and Long-Term Care of the Select Committee on Aging. Expert presentations were given on the nature and treatment of this mental disorder as well

as on the various biomedical research advancements that have been made in recent years. Testimony was also received from a number of individuals and organizations about the effects of the disease on the families of Alzheimer's victims.

The Committee's Subcommittee on Health and the Environment held one day of hearings on H.R. 3148 on August 2, 1985. Testimony was received from eight witnesses, representing seven organizations.

COMMITTEE CONSIDERATION

On October 1, 1985, the Subcommittee on Health and the Environment met in open session and ordered reported the bill H.R. 3148, as amended, as a clean bill by a vote of 12 to 1, a quorum being present. On October 29, 1985, the Committee met in open session and ordered reported the bill H.R. 3492, with amendments by a recorded vote of 17 to 7, a quorum being present.

COMMITTEE OVERSIGHT FINDINGS

Pursuant to clause 2(1)(3)(A) of rule XI of the Rules of the House of Representatives, the Subcommittee made oversight findings that are reflected in the legislative report.

COMMITTEE ON GOVERNMENT OPERATIONS

Pursuant to clause 2(1)(3)(D) of rule XI of the Rules of the House of Representatives, no oversight findings have been submitted to the Committee by the Committee on Government Operations.

COMMITTEE COST ESTIMATE

In compliance with clause 7(a) of rule XIII of the Rules of the House of Representatives, the Committee believes that the cost incurred in carrying out H.R. 3492 would be:

Fiscal year 1986: \$10.5 million.

Fiscal year 1987: \$11.0 million.

Fiscal year 1988: \$11.5 million.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, November 14, 1985.

Hon. JOHN D. DINGELL,
Chairman, Committee on Energy and Commerce, U.S. House of Representatives, Washington, DC.

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the attached cost estimate for H.R. 3492, the Protection and Advocacy for Mentally Ill Individuals Act of 1985, as ordered reported by the House Committee on Energy and Commerce on October 29, 1985.

If you wish further details on this estimate, we will be pleased to provide them.

With best wishes,
Sincerely,

RUDOLPH G. PENNER.

CONGRESSIONAL BUDGET OFFICE, COST ESTIMATE

1. Bill number: H.R. 3492.
2. Bill title: Protection and Advocacy for Mentally Ill Individuals Act of 1985.
3. Bill status: As ordered reported by the House Committee on Energy and Commerce on October 29, 1985.
4. Bill purpose: This bill would assist states in establishing protection and advocacy systems for mentally ill individuals and promote family support groups for Alzheimer's disease patients and their families.
5. Estimated cost to the Federal Government:

[By fiscal years, in millions of dollars]

	1986	1987	1988	1989	1990
Protection and advocacy systems:					
Authorization.....	10.5	11.0	11.5
Estimated outlays.....	2.2	7.7	10.1	8.7	3.2

The costs of this bill fall within function 550.

Basis of estimate: The authorization level is stated in the bill. CBO assumes that all stated authorized amounts are fully appropriated at the beginning of each fiscal year. Outlays are estimated using spendout rates computed by CBO on the basis of recent program data.

This bill would authorize federal funds for three years to assist states in establishing protection and advocacy systems for mentally ill individuals. This bill would also require states to certify that an advocacy program had been established or that one would be established in order to continue to receive an allocation from Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) Block Grant funds.

Title II of the bill would establish family support groups for those with Alzheimer's disease and their families. The bill would also establish a national network to coordinate these groups. The level of federal involvement in the support groups and national network is not specified in the bill. Costs could result depending on the actual level of federal activity.

6. Estimated cost to State and local government: The budgets of state and local governments could be affected by the enactment of this bill. ADAMHA block grant allotments would be eliminated in states that do not establish protection and advocacy programs for mentally ill individuals. In fiscal year 1985, \$490 million was provided to 57 states and territories by the ADAMHA Block Grant program. CBO has no basis to estimate which states might not establish advocacy programs, and therefore lose ADAMHA funding.

The budgets of state and local governments would not be affected by enactment of the remaining provisions of the bill. The bill spe-

cifically states that allotments to states for establishing protection and advocacy systems would be used to supplement and not supplant the level of non-federal funds that would otherwise be made available for this activity.

7. Estimate comparison: CBO prepared an estimate for S. 974, the Protection and Advocacy for Mentally Ill Persons Act of 1985 on July 11, 1985, as ordered reported by the Senate Committee on Labor and Human Resources. The Senate bill has slightly lower funding levels for the state systems and did not change the allocation of ADAMHA block grant funds.

8. Previous CBO estimate: None.

9. Estimate prepared by Carmela Dyer.

10. Estimate approved by James L. Blum, Assistant Director for Budget Analysis.

INFLATION IMPACT STATEMENT

Pursuant to clause 2(1)(4) of rule XI of the Rules of the House of Representatives, the Committee makes the following statement with regard to the inflationary impact of the reported bill:

The Committee is unaware of any inflationary effects of the enactment of the proposed legislation. Indeed, advocacy services on behalf of mentally ill persons are anticipated to lower unnecessary use of expensive institutional services, as well as to reduce the need for medical care required by persons who are victims of neglect or physical or sexual abuse.

SECTION-BY-SECTION ANALYSIS AND COMMITTEE VIEWS

Section 101 designates Title I of the bill as the "Protection and Advocacy for Mentally Ill Individuals Act of 1985."

Section 102 sets out the definitions of terms used within the legislation.

"Abuse" is defined to include the act or failure to act by an employee of a hospital, board and care home, nursing home, or community facility for mentally ill persons in a knowing, reckless, or intentional manner, which caused or may have caused injury to a mentally ill individual. Examples of such abuse are given.

The Committee does not intend that the term "abuse" include elements of therapy that are in accordance with recognized professional standards and State and local laws. The Committee recognizes that some accepted practices may result in transient physical or mental pain. When such activities are in accordance with professional standards, as well as State and local laws, the Committee does not intend this authority to restrict therapeutic care.

"Eligible system" is defined to be the P&A system established in a State under Part C of the D.D. Act or a State mental health protection and advocacy system. A system other than the D.D. P&A system may only be designated as the eligible system if 1) it is designated by the Governor; 2) it is in effect within 90 days of enactment of this Act; 3) it provides services throughout the State; 4) it meets the requirements of Section 103(b) of this Act; and 5) it is principally supported by State funds that have been appropriated

by October 1, 1985, for the purpose of providing mental health protection and advocacy services.

It is the Committee's intent that established D.D. P&A's be the principal eligible systems on order that services commence as soon as possible and in order to ensure that services are delivered by objective agencies, external to the providers of institutional care. Further, persons whose mental illness is manifested before age 22 are currently within the mandate of the D.D. P&A system. The option for the Governor to designate a State mental health protection and advocacy system is created as a narrow exception for those few States that have a functional advocacy service in place. The Committee does not intend this option to spawn the creation of new State agencies but rather to allow those few States that have taken strong, independent action to maintain their services without requiring administrative re-organization under this Act. If a State agency is designated as the eligible system, the Committee strongly encourages the Governor and the eligible system to work to coordinate services under this Act with those provided by the State D.D. P&A. The Committee recognizes that under the terms of the D.D. Act, the Governor may redesignate a P&A system for good cause.

"Mentally ill individual" is defined to mean an individual 1) for whom a diagnosis of mental illness has been made by a professional qualified under the laws of the State and 2) who is an inpatient in a hospital or a nursing home or a resident in a board and care home or a community facility for mentally ill persons. A person meeting these criteria, however, is deemed not to be mentally ill if 1) he or she has an appointed legal guardian, conservator, or legal representative or 2) he or she is an inpatient in a hospital or nursing home in a State in which there is in effect a State protection and advocacy system similar to those created by this Act. These two exceptions to the definition of a "mentally ill individual" do not apply in a State in which the Governor has designated a State-run system as the eligible system under this Act.

The terms "legal guardian," "conservator," and "legal representative" are intended to mean individuals appointed and regularly reviewed by a State court or agency empowered under State law to appoint and review such officers. The Committee intends the terms to include only those individuals who are given authority necessary to make all decisions on behalf of a mentally ill person and does not intend the terms to include persons acting only as a representative payee, persons acting only to handle financial payments, attorneys or persons acting on behalf of a mentally ill person only in individual legal matters, or officials responsible for the provision of health services to a mentally ill person. The intent of the provision deeming persons not to be mentally ill if they have a legal representative is to avoid duplication of advocacy services on behalf of a person diagnosed with mental illness who has—through other court or State action—an effective advocate on his or her behalf.

The provision deeming persons not be mentally ill if they are inpatients in a hospital or a nursing home in a State in which a protection and advocacy program similar to those created by this Act is intended to limit the ability of States to supplant their own efforts with Federal funds provided by this legislation. States that determine their systems are similar to the provisions of 103(b) are in-

tended to use their allotment under this Act to supplement these activities by providing services for residents of board and care homes, for residents of community facilities for mentally ill persons, and for persons discharged from hospitals, nursing homes, board and care homes, and community facilities for mentally ill persons. The Committee intends that this limitation complement the provisions, described below, requiring that a State use its allotment to supplement, rather than supplant, ongoing activities.

In those few States where that the Governor designates a State mental health advocacy system as the eligible system, as described above, persons diagnosed as mentally ill and resident in one of the settings described are to be considered mentally ill, regardless of questions of other legal representatives or similar State systems. The Committee intends that in such States, the Governor and the eligible system coordinate activities with other State systems and other legal representatives in order to avoid duplicative services.

"Neglect" is defined to mean a negligent act or omission by any person responsible for providing services in a hospital, nursing home, board and care home, or community facility for mentally ill persons which caused or may have caused injury or placed a mentally ill person at risk of injury. Examples of such neglect are given.

The Committee is especially concerned that the P&A's protect mentally ill persons against unplanned or unsuccessful discharge or "dumping." The Committee recognizes that such attempts to withdraw care and services from mentally ill individuals are as harmful as neglectful isolation or inappropriate treatment, and has specifically provided a period of time following discharge (described below) in which a P&A is to continue advocacy on behalf of mentally ill persons.

"Secretary" is defined to mean the Secretary of Health and Human Services.

"State" is defined to mean each of the several States, the District of Columbia, Puerto Rico, Guam, the Northern Mariana Islands, American Samoa, the Virgin Islands, and the Trust Territory of the Pacific Islands.

"Board and care home" is defined to mean a facility licensed or regulated by a State under Section 1616 of the Social Security Act.

Section 1616 of the Social Security Act requires States to establish, maintain, and ensure the enforcement of standards for various categories of institutions, foster homes, and group living arrangements "appropriate to the needs of recipients and the character of the facilities involved," including "such matters as admission policies, safety, sanitation, and protection of civil rights." The Committee intends that P&A's work on behalf of mentally ill persons in such facilities and in similar board and care homes in which mentally ill persons reside. The Committee does not intend the references to facilities licensed under the Social Security Act to be interpreted as a limitation upon the broad range of types of hospitals, nursing homes, board and care homes, and community facilities in which P&A's are to act.

Section 103(a) authorizes allotments to eligible systems to establish and administer protection and advocacy systems for mentally ill persons. Such a system is generally allowed to contract with

other entities for activities, but is prohibited from contracting with entities which provide treatment or services (other than advocacy services) to mentally ill persons or which are not public or nonprofit private entities. If the eligible system is an agency of a State, the State may not use more than five percent of its allotment for administrative expenses. When the eligible system is not an agency of the State, no funds may be used by the State for administrative costs.

The Committee intends that P&A's provide advocacy services in the most efficient manner possible. While only fragmentary advocacy services for mentally ill individuals exist in most areas, the Committee encourages P&A's to coordinate their activities with existing services and, where appropriate, to contract with other agencies already working on behalf of mentally ill persons.

Section 103(b)(1) describes the requirements for a system to receive an allotment. These requirements include authority to investigate abuse and neglect, authority to pursue remedies on behalf of mentally ill persons, independence from agencies which provide treatment, access to facilities, access to records, an advisory board, an arrangement with the State for Medicaid information, and an annual report. One half of the members of the system's advisory board are required to be persons who have received or are receiving mental health services or family members of such persons.

The Committee intends that the authority created by Section 103 include monitoring, evaluating, and commenting upon the development and implementation of Federal, State, and local laws, regulations, State plans, budgets, policies, programs, hearings, levies, and community action which will affect mentally ill persons.

Section 103(b)(2) authorizes the system to pursue remedies on behalf of mentally ill persons who have been discharged from a hospital, nursing home, board and care home, or community facility for mentally ill individuals. The section authorizes such activity for matters that occur within 90 days of the person's or persons' discharge.

The Committee recognizes that mentally ill persons recently discharged from institutions may need the services of a P&A during the period of initial adjustment to community life. The post-discharge coverage is intended to assist such people at a time when many become lost in the cracks between institutional care and community services. This period of coverage is not intended as a limitation on the time at which remedies may be sought or as limitation on the time during which actions may extend. Other laws respecting statutes of limitations and requirements for settlement and adjudication are not intended to be altered. Rather the 90-day limit is explicitly on the time during which causes for advocacy may arise. The Committee recognizes that difficulties may arise at a time after the 90-day limit has expired and will examine the appropriateness of extending or eliminating this limit in future legislation.

During its hearings, the Subcommittee heard testimony from administrators and advocates, all of whom strongly endorsed the idea that advocacy should not terminate the day an individual leaves an institution. Particularly noteworthy was the termination of C. Pat-

rick Babcock, the Director of the Department of Mental Health of the State of Michigan, who said:

Representing a State which emphasizes alternatives to institutionalization for all mental health clients, I am sadly familiar with examples of former patients struggling to overcome discrimination in housing and in employment or who face the threat of losing income support. Far too often our community rights advisors and case managers are unable to advocate on behalf of individuals fighting to live independent of an institution. In light of these realities, I recommend that Congress develop a Federal protection and advocacy system whose benefits can be extended beyond the walls of state facilities and into community residences, community day programming services and other support agencies, both public and private.

The Committee intends that the P&A system, using protections against neglect and other available remedies also use this 90-day discharge coverage to prevent facilities from "dumping" a mentally ill person without coordinating his or her release with appropriate community resources. The P&A should help the individual make the transition to community living and avoid the possibility that—as a result of neglect, inadequate support services, and discrimination—the individual's mental state might deteriorate, forcing a return to institutional care.

Section 103(b)(3) requires that records be maintained in a confidential manner.

Section 103(b)(4) sets out restrictions on the disclosure of records to the individual who is the subject of the records. The section forbids the disclosure of patient records to the patient if the responsible mental health professional makes a written determination that disclosure to the patient would be detrimental to the patient's health. If disclosure is denied to a patient on such grounds, however, the patient or the P&A may select another mental health professional to review the information. If the second professional determines that disclosure would not be detrimental to the patient's health, the system may disclose the records to the patient.

The Committee is mindful of the difficult questions of professional ethics that are embodied by this provision. Advocates, including attorneys, are bound by most law and codes of responsibility to inform clients of information relevant to their claims. Health professionals are, however, bound by most law and codes of ethics not to do harm to patients. This conflict is made particularly difficult by the fact that in the professional-client relationships at hand, some clients will be incompetent to make decisions on their own behalf.

The Committee adopts this compromise disclosure restriction as an initial attempt to allow P&A's to proceed. The Committee urges P&A's, providers of care, mental health groups, and professional associations to study the implementation of this restriction carefully and to restrict informed consent of clients/patients as little as possible.

Section 103(c) requires that the Secretary and the State provide the P&A with the annual survey reports and plans for corrections

performed under the Medicare and Medicaid programs with respect to hospitals, nursing homes, board and care homes, and community facilities for the mentally ill.

Section 104(a) establishes a population/per capita income formula for the distribution of funds among the States. A minimum allotment is also established for the States and another for the Territories.

Section 104(b) establishes a reallocation mechanism for funds not allotted.

Section 104(c) establishes the requirements for application for allotments. These requirements include assurances that funds received will be used to supplement rather than supplant non-Federal funds and that the system's staff is appropriately trained or will be trained to provide advocacy services for mentally ill persons.

Section 104(d) establishes payment provisions.

Section 104(e) establishes requirements that the Secretary report on P&A activities on behalf of mentally ill persons.

Section 104(f) requires that the Secretary use five percent of the funds appropriated to provide training, technical assistance, and evaluation services to eligible systems.

The Committee recognizes the need for technical assistance and training in mental health advocacy to enable new staff members employed by eligible systems to carry out their responsibilities under this Act. The Committee intends that the Secretary use the funds authorized to enable appropriate organizations, knowledgeable in mental health and disability law, to provide information, guidance, resources and resource centers, and on-site assistance to eligible systems. The Committee believes that training in advocacy techniques and technical assistance could aid in the resolution of disputes early in the P&A process, thereby avoiding costly and time-consuming litigation.

The Committee also intends that the Secretary use a portion of the funds set aside under this section to evaluate the quality and appropriateness of services provided by eligible systems. The information derived from such evaluation is to be included in the report to Congress described in Section 104(e).

Section 104(g) requires that this Title be carried out through the Alcohol, Drug Abuse, and Mental Health Administration of the Department of Health and Human Services.

Section 105 authorizes \$10.5 million for fiscal year 1986 for P&A activities, \$11.0 million for fiscal year 1987, and \$11.525 million for fiscal year 1988.

Section 106 requires as a condition of receipt of the Alcohol, Drug Abuse, and Mental Health (ADM) Block Grant that a State assure that a protection and advocacy system for mentally ill persons is in place. This provision takes effect at the beginning of fiscal year 1987.

The Committee intends that this provision act as an incentive for States to plan and provide P&A services for the mentally ill in timely manner. States that do not comply with the provisions of this Title would be ineligible for ADM assistance.

Section 201 of the legislation requires the Secretary to promote the establishment of family support groups within appropriate medical and health research facilities to assist individuals with Al-

zeimer's Disease and other related mental disorders, and their families.

The Committee intends for such support groups to provide Alzheimer's patients and their families with information on the medical aspects of the disease as well as with information on appropriate care and treatment. Support services such as informal family counseling and referral services are to be offered as well. The groups are to be organized and directed by those offered as well. The groups are to be organized and directed by those professionals with expertise on Alzheimer's Disease and other related mental disorders. No financial fees may be charged to Alzheimer's Disease patients or individuals participating in Alzheimer's-related research, or to their families for the services provided by or through these support groups.

Section 201 also requires the Secretary to establish a national network to coordinate and disseminate the work of the family support groups developed through this legislation. The purpose of this network is to facilitate the exchange of information on the various issues facing Alzheimer's victims and thier families in addition to information on the progress of the individual support groups themselves.

AGENCY VIEWS

No agency views have been received on H.R. 3492.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3 of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italic, existing law in which no change is proposed is shown in roman):

(Note: this is usually done by Legislative Counsel's Office.)

ADDITIONAL AND DISSENTING, VIEWS ON H.R. 3492

ADDITIONAL VIEWS OF CONGRESSMAN HENRY A. WAXMAN

The provisions of the amendment to section 102(3)(c) regarding the definition of a "mentally ill individual" adopted by the Committee are arbitrary and unnecessarily restrictive. As worded, the amendment deems a person in an institution with a professional diagnosis of mental illness as "not mentally ill" if he or she has a guardian or legal representative.

The effect of this deeming is to render such a person ineligible for services to protect against physical, sexual, and emotional abuse. Moreover, although the amendment was adopted ostensibly to protect guardians against duplicative reviews, the effect of the change is to prohibit guardians and legal representatives from requesting assistance in the exercise of their appointed duties.

Under this amendment, parents who discover their mentally ill children are abused or neglected will be unable to request aid. Guardians who do not know the intricacies of State mental institutions will be unable seek assistance in looking after their wards' well-being. In seeking to expedite the work of conscientious guardians and conservators, the Committee has cut them off from their best chance of real help.

The amendment also ignores the possibility of circumstances in which the guardian or conservator may be involved in the abuse or neglect. Provision should be made to allow an advocacy system to act under applicable State law to petition for remedial action on behalf of the mentally ill person.

HENRY A. WAXMAN.

ADDITIONAL VIEWS OF CONGRESSMAN MICHAEL BILIRAKIS

Even though I fully recognize the extent of our deficit and the need to control the growth or expansion of spending programs, there are health areas which far exceed budgetary concerns and require attention and compassion.

Studies have indicated that there are significant instances of abuse and neglect of the mentally ill in residential facilities throughout the nation. This is also true in nursing homes. These sorts of problems can't wait until we have a balanced budget, but rather, require our immediate attention. There are many areas where cuts in spending can be made without denying help to vulnerable groups. Considering the broad jurisdiction of the Committee on Energy and Commerce, there is no doubt in my mind that we will meet with success in finding \$11 million for the next three years to fund this program.

In addition to abuses against the mentally ill, we have another group of individuals who have been neglected for too long. These are Alzheimer's victims and their families. The provision in this bill which promotes the establishment of support groups for families of Alzheimer's victims and their families is a step in the right direction. Basically, I envision the establishment of support groups in university medical centers and in other appropriate health care facilities which receive federal funds and which conduct research or provide services to victims of Alzheimer's disease. It is quite logical that experts in the Alzheimer's field will be able to provide expertise and support that will be invaluable to families.

I do not believe it is too much to ask of researchers or doctors receiving the benefit of federal funds to donate some time to the families of Alzheimer's. Even though I applaud the efforts of researchers in seeking the cause and cure for this insidious disease, I believe there is a human element oftentimes overlooked in the research environment and that is the needs of families. These are not organisms to be examined under a microscope, but individuals watching a loved one deteriorate into a tortured soul. One cannot appreciate the torment a family undergoes when Alzheimer's strikes until you have talked to those who must care for the victim 24 hours a day. I assure you their lives are a living hell. They need as much attention to maintain their sanity as the victim himself.

The Alzheimer's Disease and Related Disorders Association has been doing some fine work with support groups and I believe additional support groups in research or care facilities will supplement their efforts. The statistics on Alzheimer's verify the necessity of additional support groups. It is my hope that the Secretary of Health and Human Services will consult with the ADRDA on the establishment of effective support groups.

MIKE BILIRAKIS.

DISSENTING VIEWS ON H.R. 3492

We recognize that there have been a number of instances of abuse and neglect of the mentally ill at various residential facilities throughout the country. We also recognize that currently established advocacy programs for the developmentally disabled and the mentally ill have been successful in curtailing some instances of neglect and abuse.

However, we are acutely aware that 1985 is not the appropriate time to authorize new appropriations for new programs. Although this program will *only* cost \$33 million over the next three years, the deficit total can increase insidiously and dramatically without anyone knowing it if Members are not determined to be fiscally responsible by holding the line against new Federal spending.

There may be a time when the Federal Government can afford to pay for the advocacy services authorized under this bill. We regretably believe that it cannot now.

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ED MADIGAN
CARLOS J. MOORHEAD.
BILL DANNEMEYER.
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JACK FIELDS.
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